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ABSTRACT

This paper reports on a study of the factors influencing the educational placement choices of 25 rural parents of children who are deaf. Specifically, the study: (1) traced the placement decisions from the time their child's hearing loss was first documented to the transition periods into elementary and middle school; (2) identified the resources that parents utilized in making these decisions; and (3) explored the various parenting styles that emerged as families made educational choices. Questionnaires and parent interviews were utilized in rural areas of Georgia, Kentucky, Louisiana, North Carolina and Tennessee. Section 1 documents parent responses and summarizes the study results concerning the initial "shock" of the diagnosis; resources parents used; issues in the transition into elementary school; issues in the transition into middle school; styles of parenting; and advice to other parents. Section 2 offers conclusions and samples of parent comments, while Section 3 offers background information on educational placement options, federal legislation, and rural special education. Finally, Section 4 provides more details about the study's research design, population sample, and data analysis. A glossary of terms is provided. (Contains 50 references.) (DB)

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Sharing Results

A Look at Rural Families Weighing Educational Options

Identifying the Factors that Influence Parents as They Make Educational Placement Decisions for Their Children Who Are Deaf

by
Vicki L. Wolfe, Ed.D.

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An Introduction to the

Sharing Results

Series

"Sharing Results" is a series of occasional papers that describe the results of work undertaken by the Clerc Center in its three priority areas of literacy, family involvement, and transition from school to postsecondary education and employment. The focus of each of these papers is determined through an extensive public input process with parents, educators, service providers, and researchers throughout the country. The Sharing Results series includes three kinds of papers:

1. descriptions of critical needs in the Clerc Center's priority areas and the processes used to identify those needs,
2. descriptions of the results of collaborations between the Clerc Center and other schools and programs to develop and implement innovative approaches to some of the persistent challenges of the Clerc Center priority areas, and
3. extensive descriptions of the evaluation of selected innovations. Program evaluations provide information to help program planners determine whether an innovation would be appropriate for their program.

It is hoped that the Sharing Results papers will provide valuable information and ideas to parents, educators, service providers, researchers, and others interested in the education of deaf and hard of hearing children.

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About the Author

Vicki L. Wolfe completed her dissertation studies at The University of Tennessee, in Knoxville, during the spring of 1999. Funding for her research study was received through Gallaudet University's Pre-College National Mission Programs (now the Laurent Clerc National Deaf Education Center). Wolfe taught elementary-age children who are deaf for a number of years and worked as a graduate research assistant for the Postsecondary Education Consortium at The University of Tennessee during her graduate studies. She and her husband, Derick, are the proud parents of an adopted daughter who is profoundly deaf. Wolfe is currently chair of the Education Department at Southeastern Bible College in Birmingham, Alabama.

A Look at Rural Families Weighing Educational Options

Identifying the Factors that Influence Parents as They Make Educational Placement Decisions for Their Children Who Are Deaf

By Vicki L. Wolfe, Ed.D.

Introduction

This paper describes some of the factors influencing the educational placement choices made by parents for their children who are deaf. It shares both the personal responses of parents and the overall conclusions drawn from a study that sought to discover the specific kinds of information and support that parents need. The study:

- traced the placement decisions of parents from the time their child's hearing loss was first documented to the transition periods into elementary and middle school,
- identified the resources parents utilized in making these decisions, and
- explored the various parenting styles that emerged as families made educational choices.

The goal of this work is to increase understanding among educators, other professional service providers, and families about the concerns of parents and the information they need in making educational placement decisions for children who are deaf. Research addressing the factors that contribute to the placement choices made by parents, and descriptions of the resources they utilize, remains extremely limited. Educators and professional service providers as well as other parents can greatly benefit from information that focuses on the personal experiences and concerns of parents facing the task of making choices about their child's education.

To gather information the author utilized questionnaires, and a total of 25 parent interviews were conducted in predetermined rural areas of Georgia, Kentucky, Louisiana, North Carolina, and Tennessee. This research sample included parents who had chosen a wide range of communication options, as well as educational placements, for their children. Parents who participated in the study responded to questions on the following topics:

- the resources available to families with children who are deaf,
- their role on the **Multidisciplinary Team**, and
- the positive and negative influences that had an impact on the quality of educational services their children received.

(Please note: Bold terms are defined in the Glossary in the Appendix.)

Parents' responses to questions on these topics—many of them shared here—can assist school systems in building better parent-professional relationships, increase support for other parents of children who are deaf, and translate to suggestions for how local education agencies (LEA) can better serve families with children who are deaf. The information shared here can assist professionals in understanding the support needs of families and may act as a catalyst for strengthening networking systems among parents, professionals, and other service providers. Finally, parents faced with making their first educational placement decision or those in the midst of a transition period (i.e., elementary school to middle school) can benefit from the past experiences and valuable insights of other parents with children who are deaf.

Pseudonyms and general terms are used for names, school systems, and places throughout this paper to ensure anonymity.

Section 1

Parent Responses and Summary of the Study Results

Throughout the study, the parents interviewed said they found themselves on a journey marked by "constant change" starting with the diagnosis of their child's hearing loss. Many of the parents expressed shock and frustration upon learning of their child's deafness, and in coping with the educational and communication decisions necessary in the child's earliest years.

The resources that families employed when gathering information about deafness and related issues included:

- themselves
- family and friends
- medical professionals
- educational professionals

Parents reported that a number of these resources proved valuable; others were ineffective.

As time progressed, the families faced transition periods in which their attention changed to focus on managing the educational goals and placement of their child. The transition to elementary school introduced them to the Multidisciplinary Team (M-Team), while the transition into middle school shifted their focus to school facilities, scheduling, and the child's level of responsibility.

A pattern emerged from the research that identified three styles of parenting:

1) Trusting Self
2) Trusting Others/Trusting Self
3) Trusting Others

Because of their own experiences, parents in the study were able to offer advice to other parents with children who are deaf. Their recommendations include:

- research and explore all options
- be realistic
- become an advocate
- practice patience

As the quotations and discussion in the sections that follow so vividly illustrate, a great deal can be learned by reflecting on the successes, as well as the failures, of the parents in the study as they lived through the various developmental stages of their children's lives. Some of the resources utilized by the families proved effective, while others did not. By examining the practices and interactions between parents of children who are deaf and resources available at the local and state levels, others may gain insight into avenues for improving the communication and educational placement options available for families of children who are deaf.

The research also provides important information by documenting similarities and differences among the families as they made educational decisions. Perhaps this study can help professionals develop a better understanding of the various types of parenting styles as well as develop strategies to best meet the individual needs of each family.

The Initial "Shock"

Families spoke repeatedly about the instability they experienced throughout the first five years of their children's lives. This period of change began with the initial diagnosis of a severe to profound hearing loss and continued until the child entered preschool and/or kindergarten. One parent described her frustration: *Sometimes I cry because it is so hard.... I am tired of having to do things different. I cry because we don't have the normal, everyday life, you know.*

Parents found themselves asking:

- What does it mean to be deaf?
- How will this affect our family?
- How will our child communicate?
- Where will our child attend school?

These questions are among the first that families encountered upon discovering their children were deaf. Parents faced the ominous task of coping with their children's deafness, while at the same time making critical educational choices.

The majority of families told of the grief and fear they felt when they realized their children had severe to profound hearing losses. One parent described her reaction to the audiologist's explanation of her child's **audiogram**: *She had to look me in the eye and say, 'Your child has a severe to profound hearing loss.' That was the last thing I heard.* Another family experienced a similar reaction: [Father speaking] *Yes, it was shocking.*

[Mother speaking] *We didn't want her to be deaf and then we decided we got to. What do we do about it? Where do we go from here?*

As the families began the process of coming to terms with their children's disability, they often sought the advice of others when trying to learn about deafness.

Resources Parents Used

A study conducted by Bernstein and Martin (1992) asked 128 parents of children attending residential schools for the deaf how they had obtained information about educational placement options and the reasons for choosing a residential placement. The results indicated that 72 percent of the parents had received some information pertaining to educational placement options for children who are deaf.

However, a large percentage of these parents reported that the information they received was limited to one specific placement option. In many of the cases, no discussion of multiple placement options occurred. These findings suggest that some professionals and service providers within the field of deafness don't always provide parents with sufficient information about the legally mandated educational placement options available to their children.

Some of the educational and communication advice offered by resources, including family, friends, and educational and medical professionals, proved beneficial; other advice was biased or slanted toward a particular ideological opinion or philosophy.

One parent spoke highly of the early intervention program on behalf of her son: *They got down to the nitty gritty. They had an excellent program to get us going. If we had not had that to get us started, to educate us on all the methods, John* [her son] *would not be where he is now.* But not all parents considered the information they received to be helpful. In retrospect, some of the parents expressed regret about listening to the advice of others. As one parent said: *But now looking back, I can see that there was a lot of things let go there* [the local county school system] *that should not have been. Knowing what I know now, things were not done right.*

Themselves

Frequently the parents themselves sought advice from others in learning about deafness, modes of communication, and school placement options. The majority of parents had detected a hearing problem and quickly sought medical advice. After their child's hearing loss was diagnosed, a few of the parents began to research deafness and related issues, such as communication and school options, on their own.

One parent went to the local board of education and petitioned for a teacher of deaf and hard of hearing children: *We started her at South Elementary. I went to the board trying*

to get a teacher for her. Another parent began contacting social organizations that had a reputation for helping children with disabilities: *I got on the phone and looked through the phone book and called Shriners.... I knew the Scottish Rites Hospital helped handicapped people. I thought, surely someone can tell me something.*

Family and Friends

In many cases, friends and family members became instrumental in furnishing the parents with references to professionals and other service providers working with children who have disabilities.

> [Mother speaking] *There was nobody there, and we had to go to Smithville; we had to start finding places to call. Where do you start? The only thing we knew about was, somebody in your family knew about....* [Father speaking] *John got us in touch with the Children's Hospital.*
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> Another parent said: *I had a friend I was working for at the time and she knew Doris and she contacted her for me. She contacted me and then we went through the state and got everything set up and she started coming in for in-home visits.*

Medical Professionals

Some parents looked to the medical profession for assistance and guidance to make decisions regarding a method of communication for their children as well as the types of school programs available.

In this particular study, a few of the physicians responded quickly to the parents' concerns and handled them with sensitivity and competency. The majority of physicians, however, did not act on the concerns of the families. Frequently, the physicians considered parents "over-anxious" or "over-protective."

A few of the parents shared their experiences:

> *We noticed when he was about eight months that he did not hear so we took him back and forth to the pediatrician. We did go to an audiologist within a month or two....he* [the audiologist] *tested his hearing and said he could hear, that he was not language delayed. It was because we were bad parents. We didn't make him talk.*
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When Allen was nine months old, we first suspected. I called his regular pediatrician and they sent us to an ENT [ear, nose, and throat physician]. *They started doing the brainstem testing and all of that. We knew there was a problem from their testing.*

We went to an audiologist to do the ***ABR*** [Auditory Brain Stem] *and then the ENT was called once they showed a mild* [progressive] *loss. That is what he told us: this child needs to go to a deaf school and learn sign language.*

Educational Professionals

When families turned to the education profession for advice, some received a wide range of options to explore. As one parent said: *We visited the three schools that they gave us. We visited all three of them* [referencing an **oral** county program, a **Total Communication** day program, and an oral **day school**].

One parent expressed admiration for the school administrator who gave her guidance and counsel: *It was not like she was saying, 'You have to come here.' She gave us the options. She showed us different ways of learning.*

Other parents, however, were presented with limited choices. As one parent said: *We were not given many choices* [referring to programs for children who are deaf]*...this is what we've got.... Looking back, I would've liked to have had a choice.*

Issues in the Transition into Elementary School

During the elementary years, the context of "constant change" moved past early intervention issues to programmatic-related matters. Although change continued, the parents began to express concerns over the "unpredictable" nature of their changing circumstances. Many of the parents felt their children's educational programs were subject to change from year to year. One parent voiced her frustration:

But you can never sit down and relax because you know the next year is coming. And even though you start out the year and you kinda take a couple of breaths, we still know that next year is coming.

Multidisciplinary Teams

When the time came for the children to enter a formal educational program, members of the multidisciplinary teams met to discuss the individual needs of the children and to determine appropriate school placements. After the initial placement, the teams held

annual meetings to review the children's performances and evaluate the effectiveness of the current placements. Parents often referred to these meetings as the "Big M-Team."

Some parents described the M-Team as being calm and very productive while others expressed frustration with and distrust of the process. The following statements present a stark contrast between parents who had positive experiences working with the M-Teams and those who had negative encounters:

> *We have never had a bad M-Team. I mean, I have talked to other parents who have nightmares It is like they get broadsided.... I mean they are told your child is not appropriate at this and it's like they get kinda hit.*
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> *They were wonderful. Any questions that we had—they explained everything. They showed us what the* ***IEP*** [Individualized Education Program] *meant and what they were going to try to do from this date to the following date of the next year.*
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> *It was horrible. They were very rude, defensive. They wanted him here. They wanted to put him in, like I said, in a classroom with mentally handicapped kids. There is nothing wrong with his mind; he can't hear, but there is nothing wrong with his mind. There is nothing he can't do.*

Socio-Political Issues

Due to the low incidence of deafness, many rural school systems struggle to find qualified administrators, teachers, and support service providers. Limited funding, budgetary restrictions, and low pay scales often result in understaffed school programs serving students who are deaf. Two families expressed their resentment about high-ranking county administrators whom they felt lacked the qualifications of an effective leader:

> [Mother speaking] *I don't think he has compassion for the children. It takes somebody who has the knowledge, knows what they are doing, and knows the law and all that. But above all, I think it has to be somebody who has the heart, and I don't believe he does. I would start with him and I'd kick his butt out. I would tell him, 'You know, either you start thinking about the kids first, or take a hike.'* [Father speaking] *It's called* ***politics*** [emphasis added].
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> *They are very aware of their restraints money-wise, personnel-wise, facility-wise. I find they are not generally thinking of my child in the meetings. I don't*

understand why people in the IEP work for the school system, but I have always been able to get what I felt like he needed or close enough [child attends oral, public school program].

One parent described the difficulty rural counties face when searching for qualified teachers for students who are deaf: *They are still looking for a teacher of the hearing impaired. See, he really needs it, but of course it is such a rural community. It is hard to get anybody.*

Another problem, which can negatively impact school systems, is the lack of standards for assessing the competencies of support service providers. One parent discusses how the absence of standards opened the door to hiring unqualified staff such as sign language interpreters:

> *They did not have qualified interpreters and I do not understand how it is state per state. No one tests the interpreters. There were some deaf children who went in who knew more sign language than the interpreters.*

All schools, whether residential or public, were subject to these socio-political concerns. Nevertheless, parents whose children attended public schools had the most concerns about high teacher turnover and inadequate support service providers. The highest teacher turnover rate witnessed by families could be linked to smaller public school programs in rural areas of the country.

Because **residential schools** do not necessarily require the service of sign language interpreters, inadequate support services was not necessarily a problem, but parents did express concerns about limited staffing in the student dormitories or cottages:

> *What I dislike most.... I guess a lot of times the kids are not always thought of first. Maybe something political comes into it and they kinda forget that they should be doing what is best for the children not necessarily what is best for whoever—the top dog* [child attends residential school for the deaf].
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> *It's like they don't have enough money to staff as many people as they should for the amount of kids that they have* [referring to dorms at the residential school for the deaf].

Academic Settings

Parents also noted concerns about their children's academic performance and instruction during the elementary school years. Families concentrated on the educational goals set for their children and often linked program satisfaction with teacher effectiveness. In other words, if they considered teachers competent, parents were generally accepting of the school system administration and at times compromised on some issues of disagreement. On the other hand, parents unhappy with their children's teachers

frequently criticized the school system and often displayed inflexibility in resolving differences with the school.

One parent described her satisfaction with her child's teacher's ability to administer various tests designed to measure educational performance. Although she disputed the effectiveness of some tests, the parent never made a formal complaint. Instead she chose to focus on the teacher's strengths and minimize the weaknesses:

> *The last two teachers he had in Jefferson County were really good, very good teachers. So they used the Stanford Achievement Test for the state hearing impaired. They used the KTA, which I don't particularly care for, but it helps a little bit. They have got a signing test that they gave him.... They go over all the testing, where he is at and what he is doing.*

Another parent could have filed a complaint because the school system failed to provide sign language interpreters for parents interested in the regular **mainstream** program. Instead, the mother commended the teacher's efforts and stressed the positive aspects of her child's placement:

> *She* [the teacher] *was so excited, she understood that she was getting a child with no speech and also she realized that he had no signs, but was willing to try it.... The good thing was that Jimmy had pretty much one-on-one instruction for kindergarten, first, second, and third grade because he was with her. He could not go out into the classroom because there was no interpreter.*

Parents who experienced negative encounters with teachers became frustrated and critical of the system. One such parent considered transferring her son to a previous school placement because of her displeasure with the classroom teacher:

> *The first year was a disaster. It was nothing. I mean he was so bored he would sit there and unravel his socks. She* [the teacher] *was trying to say he was Attention Deficit Disorder. I was like, I think we just need to get him back to the Smith County Day School.*

Another parent voiced disdain for her child's teacher because of the low expectations set in the classroom. She did not feel this type of teacher was an anomaly:

> *I can guarantee you that teacher will never, ever, ever teach my child again as long as I am on this earth. She is wrong; she does not need to be in there because she is one of the ones with the attitude: 'They just can't do it, put them over there in the corner.... They can't learn nothing, you know, let's just baby-sit them all day.'*

Issues in the Transition into Middle School

As the children completed elementary school, families tended to shift their focus to issues centered on managing their children's current educational goals and placement.

During the transition period into middle school, families felt that the greatest differences between elementary school and middle school centered on the facilities, scheduling, and the change in the student's responsibility. These three issues, interestingly, are ones that hearing children might face. One parent spoke of the similar experiences of her (hearing) son and (deaf) daughter:

> *I think the biggest thing in middle school—I don't think it has anything to do with the hearing-impaired program and I went through it with my son who will be a junior in high school—it is the loss of [parental] control in middle school.... They are trying to put more responsibility on the children and when they are not as responsible as they should be at times, it is like the parent is the one who feels that.*

Teachers and Academics

The majority of parents expressed satisfaction with the dedication of middle school teachers and the opportunity for their children to participate in organized sports. As one parent said: *I have felt like I have walked in with a group of people who knew my son, who actually knew what he was doing.* Another parent also was pleased with her child's teacher: *I am satisfied with the way his teacher, Ms. Jones, has really been wonderful. She seems to really be interested in Danny; you know, making him do everything and making him do it right.*

Although most families viewed the teachers as caring and dedicated, many parents expressed a desire that their children be held to higher academic standards. This was especially true of reading standards. Two parents said:

> *I guess the thing that dissatisfies me seems to be such an accepted rule that deaf people only have a reading level of sixth grade. That bothers me. I have a problem with that. If you tell children that you can only do this and this is as far as you can go. Or if you tell anyone that...then that is all they will shoot for.*

> *I want to be concerned over reading but they assured me over the years that is how it is with most deaf kids...they say, 'Ma'am you don't understand,' but starting this year it sunk in that most deaf kids don't read well. It's like you have to be a genius. It is something that is in the genes or something.*

Other parents felt their children were not encouraged to reach their full academic potential, or that academic standards were not equal to standards for hearing children:

I am not satisfied because I think he can do more than that if he is pushed because he is a child who needs to be pushed.

I know it is a good school, but it is just my feelings, not no one else's, ***it is not hard enough*** [emphasis added]. *I'm not blaming them... no one told me that they were just going to put them in there and pass them on through....*

Behavior

Families also cited an increase in behavior problems as a major area of dissatisfaction. As a parent said: *There are some behavior problems in the hearing-impaired classroom—at times pretty severe, not real severe, but at times.*

Parents whose children lived in dormitories at residential schools tended to be more outspoken about issues of misconduct. As one parent said:

These kids come from all over. You have to imagine your child [is coming] *home on the weekend, but some kids are out in this world doing just what they want and they have people do things to them. It is like, you can hope and trust in God, but you can't be there 24/7.*

Styles of Parenting

Three styles of parenting emerged from the research data. These unique styles serve as the theoretical basis for this research study and are as follows:

1) Trusting Self
2) Trusting Others/Trusting Self
3) Trusting Others

Under each of the three styles of parenting, two broad categories emerged from the data that demonstrated the differences in parenting styles. The first category (the time factor) considered the relationship between the parents' sense of time and their actions when making educational decisions. Some parents sensed tremendous pressure to act quickly while others, although aware of the importance of time, did not feel compelled to make decisions quickly.

The second category (the control factor) involved the degree to which parents thought of themselves in control of the educational decision-making process. Parents who felt in control generally exhibited more confidence and goal-oriented behaviors. On the other hand, parents who felt a lack of control over circumstances exhibited a more passive, impressionable role.

Trusting Self

Parents in this style of parenting assumed an assertive parenting role soon after learning of their children's deafness. Several of the parents included in this category were driven by the belief that early intervention was a top priority. These parents believed the sooner their children began to communicate and develop language, the better off they would be in the long run. One parent said: *I knew that language develops in the first three years...that is why I wanted the total communication. I knew she was losing out and we did not have a lot of time.*

Interestingly, several of the families included under "Trusting Self" experienced some type of disagreement with resource persons at the time of diagnosis. These encounters seemed to fuel the parents' action-oriented approach when choosing placement and communication options for their child. Consequently, these parents adopted early on a "we're in charge" attitude about their children's future. For example, one parent said: *Well, we went to X County first to see what they had, and I sit in and observed a classroom where* [sic] *they had. They wanted to put him in a classroom with the mentally retarded kids, and I told them 'No.'*

The more assertive role of these families was also evident in their role on the M-Team. One parent explained:

> *I, as a parent, am very strong to say, 'This is what I want to see happen.' I want to listen to everybody's view. I am not like, 'I, OK, I know what is right, and I am going this way,' but I also think that I know my child a little better than they do. Yes, they may be the professionals but, no, they don't live with her. I know what she truly can do.*

Trusting Others/Trusting Self

Parents with this second style of parenting were more passive during the early stages of identifying their children's hearing loss. After living through a period of crisis, these families shifted to a more action-oriented role when making educational decisions for their children. One parent made the "shift" soon after the diagnoses of her son:

> *So one morning in July, I woke up and went 'What am I doing?'...I have been letting these people tell me what to do with my child. I have been letting these people do with my kid whatever they want to do and have been going along with it. But I don't know what we are doing; I don't know why.*

After making the shift from "Trusting Others" to "Trusting Self," some parents, in hindsight, mentioned the importance of time. One parent recounted how she came to understand the importance of time after watching a friend's child regress academically: *The child lost almost a full year of learning. For any deaf child you cannot lose...I mean, time is very important.* These parents also began to develop more self-assurance as demonstrated by their evolving role on the M-Team. For example, a parent said:

I pretty much speak my mind.... I have Greg on the educational track right now. He gets bored with that vocational teaching about factories, assembly line work, and he gets bored and gets in trouble...and so I told them I did not want him in that. I told them I want him on the educational track.

Trusting Others

Parents included in the third style of parenting viewed professionals as the experts and relied heavily on their advice when making educational decisions for their children. Parents in this group were not influenced by a strong sense of time during the early stages of identification and entrance into elementary school.

As middle school approached, however, these families began to feel concern about their children's academic performance. Though some of the parents mentioned these concerns to professionals, these parents chose not to "push the issue." Once the professionals made a recommendation, they generally went along. A parent spoke of her apprehensions when the school suggested changing to a certificate track:

She [the teacher] *said instead of going diploma we should think about certificate. So we thought about it.... They said this way there would not be so much push and pressure. They* [sic] *would be at her own pace and she could learn, so we decided to do that...but I don't see how in the world could someone move up and she is still in first or second grade reading level. And she is going into sixth grade?*

Parents in this group chose to limit their control when making communication and placement decisions for their child. They treated the opinions of professionals very seriously and generally followed their lead. This does not mean the families never spoke up. They had genuine concerns about their children's education. Nonetheless, many chose not to act on these concerns. The reason parents chose not to "take action" when dealing with professionals varied among the families. Some parents seemed to lack self-confidence, while others suppressed their frustrations in order to maintain "peace" with the school system. One parent related her thoughts about living in a rural area:

You don't have a choice of a teacher being in a small place. And that is the only choice you have, as long as you are in the school district you do not want to displease her. That is another reason you want to listen to her and be nice to her so that the next year it may be better than the last one.

When discussing M-Team meetings, most of these "Trusting Others" parents felt free to contribute their opinions and concerns. Nevertheless, when describing the actual meetings, the professionals appeared to dominate the discussion of the children's goals and objectives:

Back in Florida, I did not know what IEP means, so it was helpful to sit there and hear what the teacher has to say about the child, and what the child needs to do...; so now, I

do have some knowledge, not a lot, but most of the time the teacher just wants to have coffee. It is not easy to tell them I want this and them agree to it.

They just kinda go through the papers and kinda read them to me, you know. Ask if you have any questions, kinda explain what she will be taught.

Advice to Other Parents

At the conclusion of the interviews, the parents were asked what advice they would offer to other families with young children who are deaf. The four highest-ranking responses were:

- research and explore all options
- be realistic
- become an advocate
- practice patience

Research and Explore All Options

The parents overwhelmingly expressed the need for families to research and explore all communication and educational options available to children who are deaf. Once parents become aware of their options, they must decide on the method of communication and a school placement that most effectively meets the needs of their children and families. One parent suggested that families living in rural areas should turn to the Internet to learn about available resources and educational options: *Well, the first thing is you have to search for yourself to see what is out there, what is offered.... You have the Internet now. You have places everywhere to find out what is best for my child.... We had to go outside our community to find these things.*

Two parents shared their insight into the various modes of communication and school programs for children who are deaf:

Several years ago I would have said sign language communication. Now I think I would have to determine what is the best mode for your child whether it is oral or ***ASL*** [American Sign Language] *or* ***Signed Exact English****...whether it be a mainstream or residential. It is hard for me. I know what I have done. Of course, I have experienced all of it.*

Educate themselves, learn, and try to learn about everything, not just lip-reading, Signed English, or ASL, learn about it all. Try to, you know, make yourself aware of what all is available because every child is different.

Several of the parents spoke about maintaining flexibility when making educational choices for children who are deaf:

> *I would look at all of them* [program options] *and decide which one it was that I liked best, but if it doesn't work out, change it. Nothing is engraved in stone. Nothing says since we chose this, it has to stay.* ***If it does not work, change it*** [emphasis added].
>
> ---
>
> *Always be looking at it. If this doesn't work, let's start finding something else. Don't make the kids suffer because you are too proud to change your mind.*
>
> ---
>
> *Talk to a lot of people—teachers and parents—find out all the information they can and need for their child, you know. Just go and visit different schools and find out what programs that they have.*
>
> ---
>
> *Everybody is different; every family is different. One family: ASL, that is the right thing and they should be at the deaf school; another one: an oral program, a mainstream, that is the right thing. There is no right and wrong.*
>
> ---
>
> *When you find out* [about your child's deafness], *it is better to know what all the options are. If you are comfortable with that, this is all I want for my child, that is fine. But later in life, 10 years down the line, you should not regret what you decided.*

Be Realistic

The parents also stressed the importance of families with young children who are deaf to maintain realistic expectations. As one parent suggested: *Be realistic, take what we have now and go from here and don't worry about it. Have a little faith that it is all going to work out.* Another parent agreed: *I think you must be realistic and you cannot waste any time and play around here and there.* Another parent added: *Be realistic. What is good for one person does not mean that it is good for everybody.*

Become an Advocate

The majority of parents interviewed advised other families to become active participants in the planning of their children's education. Often parents adopted an assertive role in the educational decision-making process. As one parent stated:

> *I'm a parent; I am Melissa's parent, period, and I don't know anything about the educational system and don't want to get into it. But I want to make sure Melissa gets what she wants.*

> *Be hardheaded. Be stubborn. Tell them what you want because only you are the only one looking out for your child.*

> [Mother speaking] *Know your child and stick to your guns no matter what.... Always, always know your child.* [Father speaking] *Nobody else is going to stand up for that child, your child, like you. Nobody.*

One parent expressed her sentiments on advocating for school choice: *Take her to school and fight for her.* Another parent reflected on her family's early experiences with making placement decisions for their son who is deaf: *We backed off when we should not have. So I would tell anyone to be like...a she-tiger. I think that is what you have to be and we are now.*

Practice Patience

The families who participated in the study talked readily about the daily struggles of parenting a child who is deaf. The ability to practice patience seemed to help parents endure difficult times. One parent advised: [Have] *a lot of patience and a lot of love.* Another parent said: *Patience. Patience and have a wonderful support group.*

A third parent reinforced:

> *Be patient. You have got to find your patience.... I'm talking about 12 years, it is a daily struggle. I feel, I mean, sometimes you just feel like I can't do this another day...I have just had it. But you do. You keep on.*

Section 2

Conclusion: Using this Study

The stories of the families who participated in this study illuminate the decision-making process of parents with children who are deaf. This work can be used as a foundation by other researchers who wish to expand the study by increasing the number of participants, by targeting larger geographical areas, or by examining in greater depth the overall themes and styles of parenting that emerged from the data. (See Section 4 for more details about the scope and sample of this study.)

The experiences shared by these families increase understanding of the challenges parents face in making educational and placement decisions for their children who are deaf and illustrate the strengths families bring to the educational setting. To develop true partnerships, educators and families must build relationships upon trust and respect. As Brantlinger (1991) remarks: There is a need to avoid the patronizing image of the professional expert benevolently guiding the ignorant parent (p. 257).

It is the researcher's intent that other parents, educators, and service providers take comfort in knowing that young children who are deaf develop into strong, independent individuals. The experiences shared by parents in the study offer insight and advice to others who—by choice or circumstance—find themselves thrust into the world of deafness.

Perhaps other parents with children who are deaf can benefit from the experiences and advice offered by families in this study as they reflect on their children's educational history, convey a sense of reality intermingled with hope, and offer encouragement, support, and reassurance to families just beginning to struggle with difficult communication and educational placement decisions for their children who are deaf.

Parent Comments–From Fear to Hope

The researcher felt fortunate that the families shared their joys and sorrows; in the course of conducting the interviews, the researcher experienced a range of emotions from fear to a sense of hope. To encourage individuals in the field of deafness to focus on hope instead of fear, this study is concluded with statements made by parents—statements about their reaction to the initial discovery of their child's deafness, immediately followed by statements from that same child's middle school years.

When child was nine months old:

> *It is like, I don't know. When you find out that your perfect baby is not perfect. That is like somebody hits you in the gut. I don't know, it is hard to describe.... It is like your whole world is falling apart and you don't know what to do.*

When child was 11 years old:

What he had last year [regular education with **resource room**], *it worked because he came out one of three in the fifth grade that stayed on the principal's list. I'm proud.*

When child was two months old:

I was sitting there watching the movie.... It was like I was up above watching myself watching the movie thinking, 'I have a child who will not enjoy this. I have a child who will not go to movie theaters and who will not understand what is going on and what do I do?'

When child was 14 years old:

[Mother speaking] *I am encouraged by the fact that I think Bobby is going to be just fine. Bobby's self-esteem is high...his reading and writing ability has improved....it is good enough for him to communicate on a basic level....* [Father speaking] *We now know that he can survive.*

When child was 22 months old:

[Mother speaking] *I felt like I wanted to die. I felt like I had fallen into a pit, like I was in Hell.* [Father speaking] *You always told me, like you had been cheated.* [Mother speaking] *Like I had been cheated. It felt like somebody came in the middle of the night and took my child and replaced her with somebody that looked exactly like Susy but just was not...all your hopes and dreams for your child are gone.*

When child was 11 years old:

It just amazes me that she can understand, she can comprehend all this stuff without having speech, you know, to back it up. I mean, she understands protons, neutrons, and electrons, and all that kind of stuff...it just blows my mind when she understands all this...we tell her, 'What do you want to be when you grow up?' And she says, 'I want to be a judge' and I say, 'Good, you can be anything you want to be.'

When child was two years old:

Oh, it was [as if] *the world came to an end for both of us.*

When child was 12 years old:

Math is a strength, spelling is a strength. It is rewarding to see that he is interested in it. He works on those subjects all by himself. I do not have to tell him and so far he has gotten all A's in math and spelling and it does make us feel good that there is something in which he has interests.

When child was 11 months old:

I was very saddened and it is a process…; it is a grieving process that I went through. At first I was angry…denial…guilt, but I was very angry. Then I was unsure as to what to do or how to go about doing it.

When child was 13 years old:

She is a capable learner. She is an avid reader…I can't see where she should have any problems academically if she continues to pursue her dream of being a doctor and going to medical school.

Section 3

Background: Educational Placement Options for Children Who Are Deaf

United States statistics for 1994 (the most current figures available when this study began) indicate that approximately 9,000 children who are deaf attended residential programs for the deaf, 3,704 attended day schools for the deaf, and 30,347 were enrolled in some type of local public school program (Moores, 1996). The educational placement options available to families of children who are deaf have changed drastically over the course of United States history.

Moores listed the five basic school programs available to children who are deaf as (pp. 16-18):

1. Residential schools
2. Day schools
3. **Day classes**
4. Resource rooms
5. **Itinerant programs**

Furthermore, as many as 12 variations of these five basic placements may exist in any of the fifty states. (These educational placements may also use any number of communication methods, including ASL or other sign systems, oral communication, or Total Communication.)

The array of educational options may be limited when geographic service areas are taken into consideration. Families residing in geographic areas where services for children who are deaf are severely limited may experience a reduction in availability of educational options. Brantlinger and Guskin (1987) noted that parents of children with low-incidence disabilities and/or those who reside in rural areas experience problems obtaining suitable services for their children. Urban areas generally offer a wide range of educational programs for children who are deaf. In contrast, more remote areas are frequently less affluent and characterized by having limited personnel in specialized fields, less educational expenditure per child, and fewer community resources.

Federal Legislation

One of the most significant factors in the expansion of program options for individuals who were deaf during the twentieth century was the passage of legislation protecting the rights of individuals with disabilities. The U.S. Congress passed **Public Law 94-142** (The Education for All Handicapped Children Act) in November 1975. This law required state and local agencies to

provide appropriate educational services for disabled children and youth from the ages of three to 18.

One of the major components of this legislation influenced the educational placement options (see **Educational Placement Options** section above) for children who are deaf by establishing the concept of least-restrictive environment. This section of the law states that, as much as possible, handicapped children should be educated with non-handicapped children. Another important feature of the legislation required the development of an annual Individualized Education Program (IEP) for all children receiving special education services (Cantor & Cantor, 1995).

The passage of **Public Law 99-457**, in September 1986, extended the age of eligibility for special education services to include children from birth to three, and to their families. Public Law 101-476 extended the period of eligibility for special education services to age 21. The enactment of PL 94-142 and subsequent re-authorizations (including PL 101-476 and the **Individuals with Disabilities Education Act [IDEA]** of 1990 and 1997) reflected a continuing evolution in the approach to educating individuals who are deaf (Moores, 1996). Residential schools and day schools are no longer the only placement options for parents to consider. Other types of educational options av able for children who are deaf include day classes, resource rooms, itinerant programs, private schools, and home schools. As the quantity of options for children who are deaf continues to increase, questions of effectiveness and quality must also be addressed. More specifically, these questions require attention:

- Do all parents have access to these types of programs?
- What differences exist between urban and rural settings with regard to availability of programs, quality of service (including student access to information and communication), and student population?

Rural Special Education

Rural schools comprise the majority of the nation's school systems and remain extremely diverse (Helge, 1984a). With the passing of federal legislation, rural schools have been forced to address the educational needs of children with disabilities within the local school system.

Rural school districts serving students who are deaf often face unique problems. Because of the low incidence of deafness, these districts lack the critical mass of students needed to ensure proper grade-level placement (Moores, 1996). Often teachers are required to teach a small group of children with varying degrees of hearing loss and at multiple grade levels. Other problems that may plague small rural districts include a lack of qualified personnel, inadequate transportation, and reduced funding.

A study conducted in 1990 by Stone (cited in Wengerd, Hayes, & Luetke-Stahlman, 1995) found that teacher turnover rates in rural areas are 30 to 50 percent annually, and the most common reason cited for teachers leaving centered on feelings of isolation. In rural districts many of the educators who provide services to students with disabilities do not have specialized certification

or training in deafness. Consequently, many educators are issued "emergency certification" in order to fill positions requiring a special educator (Helge, 1984a).

Parents in these districts must wrestle with questions such as: If the professionals and service providers working with these students who are deaf have no specialized training in the area of deafness, how can they adequately inform parents about the educational placement options available to their children? Furthermore, are they equipped to assist the parents in assessing the individualized needs of children passing from one educational level to another?

Rural school districts, however, do have certain advantages when compared to urban settings. On the positive side, rural districts often have a relatively high trust factor, close family ties, a sense of community, and a willingness to volunteer in helping individuals with disabilities (Helge, 1984a). Another conceivable advantage of working in rural settings is that special education teachers often have the same group of students over a period of several years. In that environment, teachers may enjoy watching the children grow and mature from year to year and develop a special bond with pupils (Wengerd et al., 1995).

Section 4

More Information About the Study

Research Design

This study consisted of two phases. Phase I included a participant questionnaire that contained a demographic information section and a Likert Scale. All participants were asked to complete the questionnaire prior to Phase II of the study.

The purpose of the Likert Scale was to provide an overview of the major areas of satisfaction and/or dissatisfaction among families parenting children who are deaf. Because the majority of parents tended to respond in the Strongly Agree or Agree category, overall areas of dissatisfaction were not noted. Therefore, the data collected from the participant interviews became the primary means of analysis. The personal interviews seemed to more accurately reflect the experiences of the parents and provide clear distinctions between the major areas of satisfaction and dissatisfaction among parents.

Phase II of the study consisted of a semi-structured interview, combined with both open- and closed-form questions used during the scheduled interviews with parents. Although a semi-structured format was used during the interviews, further exploration into areas that warranted additional investigation was allowed. In these instances, the researcher simply asked "Tell me more about ____?" or "How did that make you feel?" The use of both a pre-designed questionnaire and a semi-structured interview format allowed the research questions guiding the study to be addressed, while at the same time permitted flexibility and some latitude in asking the questions.

Questions

The study addressed the following questions during the data collection phase:

- Who were the initial contacts that provided parents with advice and information concerning educational placement options for children who are deaf?
- What were the major factors that influenced the parents' initial educational placement decision for their child?
- Did the same factors that influenced the parents' initial placement decision play a vital role during the transition period from elementary to middle school?
- As the parents reflect on their child's educational history, what resources or support systems do they consider the most valuable?

- What aspects of their child's current educational placement are parents most pleased with? Most displeased with?
- What advice do parents of middle school-age children who are deaf have to offer to other parents with young children who are deaf?

The Population Sample

A brief questionnaire consisting of a demographic section and a series of rating scale statements was mailed to all participating parents prior to the interviews. Data obtained from the questionnaires and parent interviews were analyzed by the use of both quantitative and qualitative research methods in order to gain insight into the educational decision-making processes used by parents on behalf of their children.

For the purposes of this project, parents with children enrolled in middle school during the spring and fall of 1998 were chosen as the main focus of this study. These families were chosen because the parents had moved beyond the initial placement decision, had several years of experience working with the M-Team at their children's school, and could share their experiences in handling their children's transition into early adolescence. The researcher especially sought to answer these questions:

- Had the parents' decision-making patterns shifted from elementary to middle school?
- What resources did these parents utilize when deciding on the child's educational placement for middle school?

Although both hearing parents and parents who are deaf were invited to participate in the study, the first parents to meet the criteria for participation were all hearing. (This did not allow for comparisons to be drawn between deaf and hearing parent groups.)

The families in the study also lived in "rural" and "other urban" (as defined by the U.S. Census Bureau) areas of Georgia, Kentucky, Louisiana, North Carolina, and Tennessee. According to the Census Bureau, one of the following criteria must be met in order for a family residence to be classified as rural:

- Parents must live in a town or city with a population of 2,500 or less as recorded by the United States Census Bureau.
- Parents must live on a "rural farm" (earning $1,000 or more from agricultural product sales each year).
- Parents must live in areas with less than 1,000 people per square mile (unless the territory eliminates an enclave or closes an indentation in the boundary of an urbanized area).

The classification "other urban" includes towns with populations greater than 2,500 but excludes large urbanized areas, central cities, and urban fringe areas. A computer-generated list of places

provided by the Census Bureau was used to determine whether a potential participant's address fell under either the "rural" or "other urban" classifications; for this study, the term "rural" was used to combine the two classifications.

Participating School Systems

All school systems serving students who are deaf within the targeted states were asked to send out a packet about the research project to parents. If a school agreed to assist in the research project, they were responsible for disseminating the research packets to all parents of middle school-aged children who are deaf. The packet of information contained a letter of support from the participating school system, an information sheet describing the details of the research project, a letter of informed consent, and a response card. Once the parent returned the response card indicating a desire to learn more about the study, he or she was contacted by telephone.

A total of 25 parents from rural areas within the targeted states participated in the study. The interviews included families whose children were attending residential schools for the deaf or other types of public school programs for the deaf. The children's communication methods included various forms such as oral only, Total Communication, and some type of manual communication (ASL, Signed English, or a combination). It should also be noted that several of the families had chosen **cochlear implants** for their children. The interviews were conducted within the parent's personal residence unless the parent preferred an alternate site. For purposes of confidentiality, only the parents and the researcher were allowed to participate in the audiotaped interviews.

Defining Deafness

At the outset of the study the definition of a person who is deaf was defined as: one whose hearing is disabled to an extent (70 dB or greater) that precludes the understanding of speech through the ear alone, with or without the use of a hearing aid (Moores, 1996). Since four of the families indicating a desire to participate in the study had chosen cochlear implants for their children, the above definition was no longer adequate. These families viewed the cochlear implant as one of the resources that they had utilized during the course of their children's education. To exclude this population, based solely on the fact that their children at some point in time may begin to understand speech through the use of the implant, would have discriminated against this particular parent group. In order to level the playing field, the author adopted the following definition: a deaf person is one whose hearing is disabled to an extent of 70 dB or greater. All parents participating in the research study provided a copy of their children's most recent audiogram or other official documentation to verify that their children had a severe to profound hearing loss.

Data Analysis

A qualitative approach to research allowed the researcher to describe in great depth the feelings and reactions of parents when their children were first diagnosed as deaf, and the experiences they faced as their children progressed from elementary into middle school. The data obtained from the personal interviews was reported in the participants' own words through audiotaped recordings and transcriptions. The text of the interviews served as the primary source for interpreting and analyzing the data. Reading and re-reading the transcripts identified thematic data by noting common "threads" emerging from individual stories.

According to Schumacher and McMillan (1993), a theme analysis describes specific and distinctive recurring qualities, characteristics, subjects of discourse, or concerns expressed (p. 508). Once these themes were recorded and coded, a timeline was formulated to trace each parent's actions during communication and educational placement decisions.

Because this study sought to better understand the "process" that parents go through as they make educational placement decisions for their children who are deaf, a qualitative, **grounded-theory** approach to the research was implemented. The grounded theory method is a systematic discovery of theory from data obtained in the social domain (Brown, Maxwell, & Browning, 1990).

Every effort was made to remain true to the parents' experiences and to give a balanced account of their journey. In spite of attempts to acknowledge and lay aside personal bias, the researcher's own background and frame of reference may have entered into the interpretation of the parents' stories.

Appendix 1

Glossary

American Sign Language (ASL) - A language mostly used by individuals who are deaf that consists of visual-gestural units or signs.

Audiogram - A graph on which results of an audiometric evaluation are charted to indicate the person's ability to hear tones at each of the presented frequencies.

Auditory Brain Stem (ABR) - A painless test that involves the measurement of electric responses recorded from the hearing nerves and brain by means of small, disk-like electrodes secured behind each ear and on the forehead.

Cochlear implant - A multi-channel device that implants electrodes into the cochlear and stimulates the nerve endings. In certain cases, this technique has been known to increase the individual's ability to hear and recognize sounds.

Day classes - Classes for students who are deaf located in a public school setting where the majority of children have normal hearing. Instruction occurs within a self-contained class for children who are deaf, within the regular education classroom, or using a combination of the two.

Day school - A school located in an urban area that serves only students who are deaf. The students commute to and from school daily.

Deaf (with a lowercase "d") - As used in this document, an individual whose hearing is disabled to the extent of 70 dB or greater. (Deaf with an uppercase "d" is usually used to refer to a group of deaf people who share a culture and a language—American Sign Language.)

Educational placement options - The range of schools, programs, and other settings that offer educational services to children who are deaf.

External validity - The extent to which the research findings can be generalized to other populations.

Grounded theory - A constant comparative method of inquiry where theory is 'generated' from data sources in order to study the processes that a target group moves through as they relate their own personal experiences over time (Strauss & Corbin, 1994).

Individualized Education Program (IEP) - An individualized plan developed by the Multidisciplinary Team for all children receiving special education services. The plan must include current level of performance, instructional goals, educational services and placement, as

well as criteria for determining how instructional objectives will be met (Hallahan & Kauffman, 1988).

Individuals with Disabilities Education Act [IDEA] - http://www.ideapractices.org/idealaw.htm

Interpreter - An individual who facilitates communication between persons who are hearing and deaf or hard of hearing through the use of the deaf or hard of hearing person's primary mode of communication.

Itinerant programs - Services provided to students with disabilities by professionals who travel from school to school.

Laurent Clerc National Deaf Education Center - http://clerccenter.gallaudet.edu

Mainstream programs - Public school programs where children who are deaf are integrated with their hearing peers.

Manual communication - Communication occurring through the use of body movements, hand shapes, gestures, or an established form of sign language.

Multidisciplinary Team (M-Team or IEP Team) - An appropriate group of individuals meeting for the purpose of determining eligibility for special education services, developing recommendations for educational placement, and reviewing educational progress.

Oral communication - Communication occurring through the use of the speech mechanisms.

Parent - The individual who has legal custody of a child and who serves as the parent representative on the child's Multidisciplinary Team.

Public Law 94-142 (The Education for All Handicapped Children Act) - http://www.asclepius.com/angel/special.html

Public Law 99-457 - http://www.ed.gov/databases/ERIC_Digests/ed295394.html

Residential school for the deaf - A school serving students who are deaf and who live within commuting distance to the school, as well as those from farther distances who reside at the school. Residential students live on campus during the week and generally return home on weekends, holidays, and during the summer.

Resource - Any person or material that has assisted or continues to assist parents when making educational placement decisions for their children who are deaf.

Resource rooms - An educational setting in which children with disabilities receive direct instruction in areas needing remediation.

Rural - Term used in this study to include areas outside of large urban areas, defined by the United States Census Bureau as both "rural" and "other urban."

Signing Exact English (SEE, Signed English) - A sign language system that represents literal English.

Total Communication - A method of communication that utilizes auditory and visual information, often using signing and verbal communication simultaneously.

Appendix 2

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